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Implications for health-related quality of life**

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*Published in:*  
Epilepsy Research

*DOI:*  
[10.1016/j.eplepsyres.2019.106251](https://doi.org/10.1016/j.eplepsyres.2019.106251)

*Publication date:*  
2020

*Document Version*  
Peer reviewed version

[Link to publication in Tilburg University Research Portal](#)

*Citation for published version (APA):*

Rassart, J., Luyckx, K., Verdyck, L., Mijster, T., & Mark, R. (2020). Personality functioning in adults with refractory epilepsy and community adults: Implications for health-related quality of life. *Epilepsy Research*, 159, [106251]. <https://doi.org/10.1016/j.eplepsyres.2019.106251>

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# **KU Leuven Post-Print**

## **Personality functioning in adults with refractory epilepsy and community adults:**

### **Implications for health-related quality of life**

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N.B.: When citing this work, cite the original article

### **Original publication:**

Rassart, J., Luyckx, K., Verdyck, L., Mijster, T., & Mark, R. E. (2019). Personality functioning in adults with refractory epilepsy and community adults: Implications for health-related quality of life. *Epilepsy Research*, 159, 106251.

Post-print available at: LIRIAS KU Leuven

<https://lirias.kuleuven.be/cv?u=U0079343>

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The authors have no conflict of interest to declare.

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## Abstract

**Introduction.** Prior research has shown that people with epilepsy are at risk for a poorer health-related quality of life (HRQOL). However, patients differ greatly in how well they adjust to their epilepsy. To better understand these differences, the present study examined the role of personality. More specifically, we examined mean-level differences in Big Five personality traits between adults with refractory epilepsy and a community sample and related these traits to patients' HRQOL.

**Methods.** A total of 121 adults with refractory epilepsy (18-40 years old, 56% women) completed questionnaires on the Big Five personality traits, HRQOL, and seizure frequency and severity. Patients' Big Five scores were compared to those of a community sample matched on sex and age using paired samples *t*-tests. We conducted hierarchical regression analyses to examine associations between personality and HRQOL, while controlling for the effects of sex, age, age at diagnosis, seizure frequency, and seizure severity.

**Results.** Patients reported higher levels of neuroticism and lower levels of openness as compared to controls. In patients, seizure severity was positively related to neuroticism and negatively related to agreeableness. Finally, patients high in neuroticism and low in conscientiousness generally reported a poorer HRQOL.

**Conclusion.** In the present study, small personality differences were observed between adults with refractory epilepsy and a community sample. Patients' personality was found to play an important role in adjusting to epilepsy, even after controlling for seizure frequency and severity. Personality assessment may help healthcare professionals in identifying patients at risk for poor HRQOL later in life.

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Keywords: Refractory epilepsy; personality; the Big Five; health-related quality of life.

## **1. Introduction**

Prior research has shown that people with epilepsy typically report a lower health-related quality of life (HRQOL) as compared to their healthy peers and peers with other chronic conditions (Wang, Wang, Wang, Xu, & Zhang, 2012). Several factors may contribute to these patients' poorer HRQOL. For instance, people with epilepsy have been found to experience more internalizing problems such as anxiety and depression, which might be partially explained by the intrusive, uncontrollable nature of epilepsy (Rai et al., 2012; Tellez-Zenteno et al., 2007). The presence of epilepsy has also been associated with cognitive impairments, stigma (i.e., feeling that others treat you differently as a result of your condition), poorer educational and vocational outcomes including unemployment, and even increased mortality (Laxer et al., 2014; Marsch & Rao, 2002; Paschal et al., 2007; Quintas et al., 2012). In addition, many of these patients struggle with the adverse effects of antiepileptic drugs (e.g., dizziness, sickness, fatigue, memory deficits, and mood swings) (Faught, 2012; Laxer et al., 2014). In a recent qualitative study, patients often described their epilepsy as something that has taken over control over their lives by taking away their independence (Rawlings, Brown, Stone, & Reuber, 2017). However, patients differ greatly in how well they adjust to their epilepsy. One important factor that may partially explain such differences is patients' personality (Endermann & Zimmermann, 2009). Assessing patients' personality may help healthcare professionals in identifying patients at risk for poor HRQOL later in life and, in this way, may contribute to the early detection and prevention of problems. Hence, studying the role of personality in epilepsy may be of interest to both researchers and healthcare professionals.

While many studies have focused on the presence of personality disorders in people with epilepsy, personality traits – covering the full range of normal personality – have been relatively understudied (Zimmermann & Endermann, 2008). Personality traits constitute the basic level of the self and account for consistencies in how people behave, feel, and think across

situations and over time (McAdams & Olson, 2010). Nowadays, the most widely used trait taxonomy is the Big Five model of personality, which comprises five broad traits (Caspi et al., 2005; McAdams & Olson, 2010; McCrae & Costa, 1999). People high in *extraversion* tend to experience frequent positive moods and are typically active and dominant in social interactions. People high in *agreeableness* tend to engage in behaviors that facilitate positive and reciprocal relations with others and are typically described as kind, empathic, and cooperative. *Conscientiousness* comprises characteristics such as being planful, organized, and responsible. People high in *neuroticism* tend to experience difficulties in dealing with negative emotions and are typically described as pessimistic, anxious, and worried. Finally, *openness* comprises characteristics such as curiosity, intellect, and creativity.

Although these personality traits are generally considered to be relatively stable and unchangeable (McCrae & Costa, 1999), recent studies have shown that both positive and negative life-events, stressors, or challenges may lead to changes in these traits over time (Madigson et al., 2014; Roberts et al., 2006). The presence of a chronic illness, for instance, may require patients to rethink who they are as a person, what they want in life, their values, and their plans for the future (Charmaz, 1995; Charmaz & Rosenfeld, 2010; Oris et al., 2016). For these reasons, some researchers have conceptualized chronic illness as a biographical disruption (Bury, 1982; Williams, 2000). Unfortunately, few studies to date have examined whether adults with refractory epilepsy differ from their peers in terms of their personality traits. Existing research has focused exclusively on the traits of extraversion and neuroticism – mostly using Eysenck’s personality model (Eysenck & Eysenck, 1990), being a precursor to the Big Five model – or has looked at other self-related concepts. These studies have found that people with epilepsy are more at risk for certain personality disorders (Swinkels et al., 2003), a poorly integrated or incoherent identity (Allebone et al., 2015), lower levels of self-esteem (Lee et al., 2016), and higher levels of neuroticism (Findikli et al., 2016; Shehata & Bateh, 2009; Wang et

al., 2018; Wilson et al., 2009b) as compared to their peers. Although these prior studies have provided important insights, it is important that research focuses on all Big Five traits to have a more comprehensive understanding of the impact of epilepsy on patients' personality.

Examining to what extent epilepsy may impact patients' personality is of great importance, given that prior research has related personality to various psychosocial and health-related outcomes across different chronic illnesses such as asthma (Van De Ven & Engels, 2011), type 1 diabetes (Rassart et al., 2014a), and congenital heart disease (Rassart et al., 2013). Personality traits have been found to predict these outcomes both directly and indirectly – for instance, through their relation with illness perceptions, coping, or perceived stigma (Goldstein & Holland, 2005; Margolis et al., 2018). Unfortunately, prior research linking personality traits to psychosocial and health-related outcomes in adults with refractory epilepsy is scarce. Existing research has found neuroticism to be a strong independent predictor of lowered quality of life, anxiety, and depression (Endermann & Zimmermann, 2009; Findikli et al., 2016; Margolis et al., 2018; Wilson et al., 2009a; Wilson et al., 2009b; Zimmermann & Endermann, 2008) – with effects typically being stronger than those of demographic variables such as sex and age or epilepsy-related variables such as seizure frequency, severity, and epilepsy duration (Zimmermann & Endermann, 2008). Extraversion, on the other hand, has been linked to a better quality of life and social functioning among people with epilepsy (Endermann & Zimmermann, 2009; Magolis et al., 2018; Zimmermann & Endermann, 2008) and seemed to protect patients against the adverse effects of high neuroticism (Wilson et al., 2009b). However, as mentioned earlier, in order to have a more comprehensive understanding of the ways in which personality is linked to psychosocial and health-related outcomes, it is important that research includes all of the Big Five traits.

To address these gaps in the literature, the present study had three main objectives. First, we examined mean-level differences in Big Five personality traits between adults with refractory epilepsy and a community sample matched (1:1) on sex and age. Second, we related several demographic (i.e., sex and age) and epilepsy-related variables (i.e., age at diagnosis, seizure frequency, and seizure severity) to patients' personality. Third, we examined whether the Big Five personality traits were related to patients' HRQOL, after controlling for the effects of demographic and epilepsy-related variables.

## **2. Material and methods**

### ***2.1. Participants and procedure***

As described in Luyckx et al. (2018), patients were selected from the database of the Epilepsy Centre Kempenhaeghe – a tertiary referral center in the Netherlands – using the following inclusion criteria: (1) diagnosis of refractory epilepsy, (2) 18-40 years old, and (3) Dutch-speaking. Patients not being able to complete the questionnaires because of insufficient cognitive abilities (a score < 70 on the Wechsler Adult Intelligence Scale) were excluded from the study. A total of 358 patients met the inclusion and exclusion criteria and were sent a set of questionnaires and a prestamped return envelope by surface mail. In addition, all patients were asked to complete an informed consent form. Patients who did not return the completed questionnaires were contacted by telephone by the research team. The study protocol was approved by the authorized medical ethical commission (METC Midden Brabant; date 04-19-2016).

A total of 121 patients, aged 18 to 40, returned completed questionnaires, which resulted in a response rate of 34%. Mean age at diagnosis was 14.64 years ( $SD = 9.19$ ; range = 0-36; median = 14; IQR = 15). The average number of seizures in the past month was 4.63 ( $SD = 14.08$ ; range = 0-120; median = 0; IQR = 4). With respect to seizure severity, the mean score was 22.38 ( $SD = 28.17$ ; range = 0-90; median = 0; IQR = 49.55), with 31% of the sample



scoring above the threshold of 40, pointing to severe seizures (Choi et al., 2014). All 121 patients could be matched (1:1) with a control participant from the general population, based on sex and age. Control participants were selected from existing datasets and were recruited in different settings, such as schools, companies, and through social media. Demographic information on the patient and control sample is presented in Table 1. As shown in Table 1, the patient and control sample differed significantly in terms of civil status, employment status, and educational level. More specifically, patients were more often unmarried, had a higher chance of being disabled, were less often working full-time, and had a lower educational level as compared to their peers in the control sample.

### **2.1. Measures**

In both the patient and control sample, we measured the Big Five personality traits with the shortened Dutch version of the Big Five Inventory (BFI-25; Denissen, Geenen, van Aken, Gosling, & Potter, 2008a; Gerlitz & Schupp, 2005). Each of the Big Five personality traits were assessed using five short-phrase items, rated on a Likert scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Sample items include: “I see myself as someone who is outgoing, sociable” (extraversion), “I see myself as someone who has a forgiving nature” (agreeableness), “I see myself as someone who perseveres until the task is finished” (conscientiousness), “I see myself as someone who can be tense” (neuroticism), and “I see myself as someone who can be inventive” (openness). The original 44-item version of the BFI has previously demonstrated strong internal consistency, test-retest reliability, convergence with longer Big Five measures, and self-peer agreement (Denissen et al., 2008a; Soto & John, 2009). Prior research has shown that the 25-item and 44-item versions of the BFI are highly related, with correlations between scales ranging from .85 to .95, providing support for the convergent validity of the BFI-25 (Boele, Sijtsma, Klimstra, Denissen, & Meeus, 2017). In addition, prior research in other chronic illness populations has demonstrated high temporal

stability of the BFI-25 scales, with stability coefficients ranging from .62 to .83 over a 1-year period (Rassart et al., 2018). Finally, the internal consistency of the BFI-25 has been found to be relatively low (Boele et al., 2017; Gerlitz & Schupp, 2005; Rassart et al., 2018). However, relatively low internal consistencies are rather common in brief measures that aim to measure the broad Big Five dimensions (Boele et al., 2017; Denissen et al., 2008b).

The Liverpool Seizure Severity Scale (LSSS) was used to assess seizure frequency and severity in the patient sample (Baker et al., 1991; Cramer & French, 2001). Seizure frequency was assessed using a single item, whereas seizure severity was measured by the LSSS 2.0 scaled summary score (Scott-Lennox et al., 2001). Patients completed the 12-item questionnaire based on the most severe seizure experienced in the past month. Scores range from 0-100 and higher scores point to more severe seizures. Prior research had demonstrated that the LSSS has excellent test-retest reliability and internal consistency (Cramer & French, 2001). In addition, the LSSS has been proven highly responsive to change, as it can detect changes in patients' seizures associated with disease progression and pharmacotherapy (Scott-Lennox et al., 2001). Finally, the instrument is able to differentiate among patients with different types of seizures, providing evidence for construct validity (Scott-Lennox et al., 2001).

Finally, health-related quality of life (HRQOL) was assessed in the patient sample using the Quality of Life in Epilepsy Inventory (QOLIE-31) (Cramer et al., 1998; Leone et al., 2005). The QOLIE-31 consists of seven subscales (i.e., seizure worry, quality of life, emotional well-being, energy/fatigue, cognitive functioning, medication effects, and social functioning) and an overall quality of life score. In the present study, we only used the overall quality of life score, with a higher score indicating a better HRQOL. Prior research has shown that the QOLIE-31 is valid, responsive to change, and has a good test-retest reliability and internal consistency (Leone et al., 2005).

### ***2.3. Statistical analyses***

First, we used paired samples *t*-tests to explore mean-level differences in Big Five personality traits between adults with refractory epilepsy and a community sample. Effect size were calculated using Cohen's *d* (Cohen, 1988). Second, we explored the role of demographic and epilepsy-related variables in the patient sample. (Multivariate) ANOVAs were conducted to examine mean-level differences in Big Five personality traits and HRQOL between men and women. For age, age at diagnosis, seizure frequency, and seizure severity, we calculated Pearson correlation coefficients with personality and HRQOL. Finally, to examine associations between the Big Five personality and HRQOL, we conducted hierarchical regression analyses. In a first step, age and sex were entered as predictors. In a second step, we entered age at diagnosis, seizure frequency, and seizure severity in the regression. In a third and final step, the Big Five personality traits were entered. Effect sizes were calculated using semi-partial correlations (Aloe & Becker, 2012; Cohen, 1988). In all analyses, the statistical significance threshold was set to  $p < .01$  to correct for multiple testing.

## **3. Results**

### ***3.1. Comparison between adults with refractory epilepsy and a community sample***

Table 2 presents Big Five mean levels for the patient and control sample. Paired-samples *t*-tests indicated that both groups differed significantly on neuroticism and openness. More specifically, adults with refractory epilepsy scored higher on neuroticism as compared to a community sample and lower on openness. All effect sizes can be considered small (Cohen's *d* < 0.50).

### ***3.2. The role of demographic and epilepsy-related variables in the patient sample***

A first ANOVA with sex as independent variable and HRQOL as dependent variable found no significant differences in HRQOL between men and women [ $F(1,120) = 3.79$ ,  $p = .054$ ,  $\eta^2 = .03$ ]. A second multivariate ANOVA with sex as independent variable and the Big

Five personality traits as dependent variables did find significant multivariate effects [Wilks Lambda = 0.85;  $F(5, 115) = 4.09, p = .002, \eta^2 = .06$ ]. However, when we examined univariate effects, none of the associations were significant at  $p < .01$ .

Next, to examine the role of age, age at diagnosis, seizure frequency, and seizure severity, we calculated Pearson correlation coefficients with personality and HRQOL. Seizure severity was positively related to neuroticism ( $r = .34, p < .001$ ) and negatively related to agreeableness ( $r = -.29, p = .001$ ) and HRQOL ( $r = -.56, p < .001$ ). Finally, age, age at diagnosis, and seizure frequency were not significantly related to any of our study variables.

### ***3.4. Associations between personality and HRQOL in the patient sample***

Table 3 presents the results of the hierarchical regression analyses. In the first step, sex and age did not predict HRQOL. In the second step, seizure severity was negatively associated with HRQOL. In the third and final step, the Big Five personality traits significantly predicted HRQOL. More specifically, higher levels of conscientiousness (small effect size, semi-partial  $r \geq .10$ ) and lower levels of neuroticism (medium effect size, semi-partial  $r \geq .30$ ) were associated with a poorer HRQOL.

## **4. Discussion**

In prior research, refractory epilepsy has been associated with adverse outcomes such as a poorer HRQOL, an increased risk for depression and anxiety, stigma, and poorer vocational and educational outcomes (Laxer et al., 2014; Marsch & Rao, 2002; Paschal et al., 2007; Quintas et al., 2012; Rai et al., 2012; Tellez-Zenteno et al., 2007; Wang et al., 2012). However, patients differ substantially in how well they adjust to their epilepsy. One important factor partially explaining such differences is patients' personality. The present study was the first to date to look at personality differences between adults with refractory epilepsy and a community sample matched on sex and age using all Big Five traits and to relate these traits to patients' HRQOL.

#### ***4.1. Personality differences between adults with refractory epilepsy and a community sample***

Although chronic illness is sometimes described as a biographical disruption requiring a fundamental rethinking of one's identity, values, and goals (Bury, 1982; Charmaz, 1995; Charmaz & Rosenfeld, 2010; Williams, 2000), we observed only small personality differences between adults with refractory epilepsy and a community sample. Adults with refractory epilepsy did score higher on neuroticism as compared to control participants, which corresponds to the findings of prior research in refractory epilepsy (Findikli et al. 2016; Shehata & Bateh, 2009; Wang et al., 2018; Wilson et al., 2009b) and other chronic illnesses such as type 1 diabetes (Rassart et al., 2014b). Patients' heightened neuroticism scores may result from the psychosocial distress that is associated with the intrusive, unpredictable seizures characterizing refractory epilepsy. As high levels of neuroticism are an important risk factor for developing depressive symptoms (Jylha & Isometsa, 2006), these findings are also partially in line with the general literature reporting increased prevalence rates of depression among people with refractory epilepsy (Quintas et al., 2012).

Furthermore, the present study found that adults with refractory epilepsy generally scored lower on openness as compared to control participants. People high on openness are typically described as quick to learn, clever, insightful, imaginative, creative, and esthetically sensitive (Caspi et al., 2005). As certain aspects of openness have been linked to cognitive abilities including intelligence and working memory capacity (DeYoung et al., 2014), future research should investigate whether the neurocognitive problems associated with epilepsy and antiepileptic medication could partially explain these lower openness scores (van Rijckevorsel, 2006; Wang et al., 2018). Finally, we did not observe any differences between patients and controls in terms of extraversion, agreeableness, or conscientiousness. Hence, we can conclude that, despite the many challenges that people with epilepsy are confronted with, they generally seemed to be as competent as their peers from the general population in developing a mature

personality. We did find some differences in openness and neuroticism between both groups approaching a medium effect size, which is in line with the model of person-environment transactions emphasizing that personality may change over time as people go through different life-events, stressors, and challenges (Roberts et al., 2005; Shiner et al., 2015; Specht et al., 2011).

#### ***4.2. Objective 2: Linking personality to demographic and epilepsy-related variables***

With respect to demographic characteristics, we found no significant personality differences between men and women. This was rather surprising given that women generally score higher on neuroticism, agreeableness, and conscientiousness as compared to men (South et al., 2018). In addition, we did not observe a relationship between age and personality. In the general population, mean-level decreases in neuroticism and increases in agreeableness and conscientiousness have typically been observed through (young) adulthood, as youngsters gain more responsibilities and take on important social roles (Luan et al., 2017; Roberts et al., 2006). However, longitudinal studies are needed to adequately chart the personality development of patients from adolescence through adulthood. Such studies should also include a longitudinal control group to investigate whether the Big Five personality traits develop differently in patients versus controls. It has been argued that the presence of a chronic illness may postpone the achievement of adult milestones such as leaving the parental home (Gledhill et al., 2000; Stam et al., 2006), which might also manifest itself in a delayed personality maturation.

With respect to epilepsy-related characteristics, we found that age at diagnosis and seizure frequency were unrelated to patients' personality. In contrast, seizure severity was positively related to neuroticism and negatively related to agreeableness. Hence, more severe seizures not only have a greater impact on patients' quality of life and emotional well-being, as observed in prior research (Quintas et al., 2012; Taylor et al., 2011), but also on patients'

personality. In sum, demographic and epilepsy-related variables were relatively unrelated to patients' personality, although some interesting associations emerged with seizure severity.

#### ***4.3. Objective 3: Associations between personality and HRQOL***

The present study demonstrated that some of the Big Five personality traits were associated with HRQOL, above and beyond the effects of demographic and epilepsy-related variables. More specifically, higher levels of neuroticism were related to a poorer HRQOL – which is in line with the current literature on refractory epilepsy (Endermann & Zimmermann, 2009; Findikli et al., 2016; Margolis et al., 2018; Wilson et al., 2009a,b; Zimmermann & Endermann, 2008). People high in neuroticism are typically described as anxious, vulnerable to stress, pessimistic and high in negative affect (Caspi et al., 2005), all characteristics which might make it more difficult for patients to deal with epilepsy-related challenges and worries. In addition, prior research has found people high in neuroticism to use more maladaptive coping strategies in dealing with illness-related challenges such as avoidant or passive coping strategies (e.g., distracting oneself or perceiving oneself as helpless) (Rassart et al., 2014a; Van De Ven & Engels, 2011). Conversely, poor HRQOL may also result in higher levels of neuroticism, as was previously found in young people with type 1 diabetes (Rassart et al., 2018). Patients struggling with epilepsy-related challenges might start to worry more and experience more negative affect – changes that may ultimately manifest themselves in higher levels of neuroticism over time (Madigson et al., 2014). Longitudinal research is needed to examine the directionality of effects.

Although neuroticism was found to be the strongest predictor of patients' HRQOL, higher levels of conscientiousness were also related to a better quality of life, above and beyond the effects of sex, age, age at diagnosis, seizure frequency, and seizure severity. People high in conscientiousness may achieve more goals, as they tend to persist when faced with illness-related constraints, potentially resulting in a better quality of life (Van De Ven & Engels, 2011).

In addition, people high in conscientiousness are typically described as attentive, organized, and planful (Caspi et al., 2005). Given that one of the domains covered by HRQOL is cognitive functioning, this might further help us understand the relationship between conscientiousness and HRQOL.

In sum, the present study uncovered important associations between some of the Big Five personality and HRQOL. However, less is known about potentially important intervening mechanisms in this relationship. In a recent study, perceived stigma (being relatively common among people with epilepsy) was found to mediate the association between personality and social well-being (Margolis et al., 2018). More specifically, higher levels of neuroticism and lower levels of extraversion were associated with greater perceived epilepsy stigma which, in turn, was associated with poorer social well-being. In other chronic illness populations, illness perceptions (i.e., how patients think about their illness) and coping (i.e., how patients deal with illness-related challenges) have been found to mediate the relationship between personality and illness-specific adjustment (Skinner et al., 2002; Rassart et al., 2014a; Van De Ven & Engels, 2011). Prior research has demonstrated the importance of examining illness perceptions and coping strategies among people with epilepsy (Goldstein et al., 2005; Shallcross et al., 2015). Yet, no study to date has looked at the mediating role of illness perceptions and coping in the relationship between personality and HRQOL in this population.

#### ***4.2. Clinical implications***

Although both researchers and healthcare professionals acknowledge the importance of addressing psychosocial issues in people with refractory epilepsy, psychosocial care is typically viewed as expensive and secondary to medical care (Mittan, 2009). However, in line with the clinical guidelines recently formulated by the International League Against Epilepsy Psychology Task Force, patients should have the opportunity to talk to a healthcare professional about their mental health at several moments in time (e.g., at the moment of diagnosis, prior to



and following the start of antiepileptic drugs, and at routine time intervals) (Michaelis et al., 2018a). These guidelines have been formulated after several meta-analyses have shown positive effects of psychological interventions on quality of life and – in some cases – seizure control among people with epilepsy (Michaelis et al., 2018b; Mittan, 2009; Tang, Michaelis, & Kwan, 2014). Cognitive and behavioral treatments, mind-body therapies, and educational interventions are the most widely applied approaches for people with epilepsy (Tang et al., 2014). Yet, few of these interventions have become integral parts of treatment in specialized epilepsy centers (Mittan, 2009). This might be partially explained by the fact that previous interventional studies have important methodological weaknesses such as the lack of a control group, low participation rates, and small sample sizes (Corrigan, Broome, & Dorris, 2016; Mittan, 2009; Tang et al., 2014; Wagner & Smith, 2006). Hence, a first step would be to test existing interventions targeting patients' quality of life in well-designed multisite randomized controlled trials to further clarify the most effective treatment components and delivery methods (Corrigan et al., 2016; Michaelis et al., 2018; Wagner & Smith, 2006).

As the present study uncovered important associations between patients' personality traits and their HRQOL, a next step would be to take into account patients' personality when selecting and implementing interventions, which is in line with so-called personality-informed interventions or personalized medicine approaches (Chapman et al., 2014). Given that specialized epilepsy centers typically have a psychologist as part of their multidisciplinary team (Labiner et al., 2010; Michaelis et al., 2018a), the psychologist could assess patients' personality through a brief self-report questionnaire in which patients are asked to rate themselves on a series of adjectives. Preferably, such personality assessment should take place shortly after diagnosis, as it may help healthcare professionals in identifying patients at risk for psychosocial problems later in life. Based on our findings, especially patients low in conscientiousness and high in neuroticism seem to be at risk. By intervening early on,

healthcare professionals may prevent the development and/or worsening of psychosocial problems (e.g., reducing the tendency to ruminate among patients high in neuroticism or stimulating goal setting and self-discipline among patients low in conscientiousness; Madigson, Lejuez., & Roberts, 2014).

#### ***4.3. Study limitations and suggestions for future research***

The present study was characterized by some limitations. First, all data was self-reported. Future research would benefit by including ratings from other informants as well (e.g., healthcare professionals or significant others) (Von Essen, 2004). In addition, future research should assess different domains of HRQOL (e.g., cognitive functioning) using objective measures (e.g., measures of intelligence, attention/working memory, or processing speed) in addition to self-report measures. With regard to cognitive functioning, for instance, prior research has demonstrated that objective testing may reveal specific memory deficits not reflected in self-reported QOL scores (Alonso-Vanegas et al., 2013).

Second, the present study is cross-sectional in nature, precluding the making of sound conclusions about developmental trends or causality. As in most studies, we assumed that certain personality traits (e.g., high levels of neuroticism) may put patients at risk for poor adjustment or, conversely, may protect patients against adjustment difficulties (e.g., high levels of agreeableness) – which is in line with the vulnerability or predisposition model of personality (Tackett, 2006). However, in a recent study among adolescents and emerging adults with type 1 diabetes (Rassart et al., 2018), associations between personality and adjustment were bidirectional in nature, with adjustment difficulties also leading to relative changes in personality over time – which is in line with the scar model of personality (Tackett, 2006). Longitudinal studies are needed to identify such bidirectional associations between personality and adjustment among adults with refractory epilepsy.

Third, the reliability of the BFI-25 has been found to be relatively poor (Boele et al., 2017; Gerlitz & Schupp, 2005; Rassart et al., 2018). Future research should use personality inventories that have been proven valid and reliable such as the NEO-PI-3 (McCrae et al., 2005) which also distinguishes among personality facets. Prior research has shown that personality facets, which represent more specific and narrow personality characteristics, develop differently over time and show differential associations with psychosocial and health-related outcomes (Klimstra et al., 2014; Soto et al., 2011).

Fourth, although patients and control participants were matched (1:1) on sex and age, both samples differed substantially on important demographic factors. Future research should take into account factors such as educational level and socio-economic status when comparing the personality traits of both groups. In addition, we did not have any information on the presence of a chronic (medical) condition in the control group. This may have confounded the current findings given that the type of control group used in comparisons – healthy controls or a community sample – has been found to impact effect size estimates (Ferro & Boyle, 2013; Pinquart, 2013).

Finally, our findings should be replicated in larger, more representative samples of adults with refractory epilepsy, as the small sample size, the low response rate, and the fact that participants were recruited from a single tertiary referral center may limit the generalizability of our findings. Low response rates may introduce sample biases because patients experiencing serious problems could be underrepresented. Such studies should also take into account additional clinical information from patients' medical records – for instance, on types of seizures, lateralization, or number of antiepileptic drugs prescribed – as we did not have this kind of information to our disposal.

## 5. Conclusions

Despite these limitations, the present study was the first to examine personality differences between adults with refractory epilepsy and a community sample matched on sex and age and to uncover associations with HRQOL using all Big Five personality traits. Although mean-level differences were generally small, patients reported higher levels of neuroticism and lower levels of openness as compared to controls. With regard to demographic and epilepsy-related variables, only seizure severity was linked to patients' personality (i.e., higher levels of neuroticism and lower levels of agreeableness). Finally, substantial associations were observed between patients' personality traits and their HRQOL, with high neuroticism and low conscientiousness being associated with poorer HRQOL. We hope that the present findings may guide both researchers and healthcare professionals working with adults with refractory epilepsy.

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## 7. Tables

Table 1

*Demographic Information on the Patient and Control Sample*

	Patients	Controls	Test statistic
<b>Sex</b>			
Men	53 (44%)	53 (44%)	
Women	68 (56%)	68 (56%)	
<b>M Age (SD)</b>	30.31 (6.50)	30.31 (6.50)	
<b>Civil status</b>			$\chi^2(4) = 13.75; p = .008$
Unmarried (e.g., single, in a relationship but living apart)	64 (54%)*	37 (31%)*	
Married/ remarried	22 (19%)	37 (31%)	
Divorced	3 (2%)	3 (2%)	
Living with a partner	23 (19%)	35 (29%)	
Other	7 (6%)	9 (7%)	
<b>Employment status</b>			$\chi^2(2) = 54.21; p < .001$
Working full-time	37 (31%)*	76 (64%)*	
Working part-time	24 (20%)	13 (11%)	
Unemployed	18 (15%)	7 (6%)	
Disabled	11 (9%)*	0 (0%)*	
Other (e.g., retired, studying)	30 (25%)	23 (19%)	
<b>Educational level</b>			$\chi^2(4) = 33.49; p < .001$
No degree of secondary education	17 (14%)*	3 (3%)*	
Secondary education degree	70 (58%)*	28 (23%)*	
College or university degree	33 (28%)*	90 (74%)*	

*Note.* \* Chi-square ( $\chi^2$ ) analyses were performed to examine whether the patient and control group differed substantially on demographic variables. In case of statistically significant  $\chi^2$ -values, we computed standardized residuals (i.e., differences between observed and expected frequencies) for each cell. Standardized residuals approximating an absolute value of two are indicative of a significant discrepancy between observed and expected frequencies and were marked with an asterisk.

Table 2

*Mean-Level Differences in Big Five Personality Traits Between Adults With Refractory Epilepsy and a Community Sample Matched on Sex and Age*

Variables	Sample		<i>t</i> -value	Cohen's <i>d</i>
	Patients	Controls		
Extraversion	3.38 (0.84)	3.35 (0.76)	0.38	0.04
Agreeableness	3.76 (0.62)	3.59 (0.58)	2.29	0.28
Conscientiousness	3.69 (0.71)	3.81 (0.63)	-1.33	-0.18
Neuroticism	3.29 (0.79)	2.95 (0.88)	3.28**	0.41
Openness	3.27 (0.70)	3.62 (0.75)	-3.42**	-0.48

*Note.* Possible range is 1-5. SDs are given within parentheses. \*\* $p < .01$ .

Cohen's *d*:  $\geq 0.20$  = small effect size;  $\geq 0.50$  = medium effect size;  $\geq 0.80$  = large effect size.



Table 3

*Hierarchical Regression Analysis Predicting HRQOL in Adults with Refractory Epilepsy*

Predictors	Standardizes Betas	Semi-partial correlations
<b>Step 1: <math>R^2</math>-change</b>	<b>.02</b>	
Age	-.04	-.04
Sex	.12	.11
<b>Step 2: <math>R^2</math>-change</b>	<b>.31***</b>	
Age at diagnosis	.02	.01
Seizure frequency	-.10	-.09
Seizure severity	-.36***	-.31***
<b>Step 3: <math>R^2</math>-change</b>	<b>.27***</b>	
Extraversion	.11	.10
Agreeableness	.15	.13
Conscientiousness	.17**	.16**
Neuroticism	-.40***	-.33***
Openness	-.08	-.07
<b>Total <math>R^2</math></b>	<b>.74</b>	

*Note.* For sex: 0 = male; 1 = female. \*\* $p < .01$ ; \*\*\* $p < .001$ .

Semi-partial correlations:  $\geq .10$  = small effect size;  $\geq .30$  = medium effect size;  $\geq .50$  = large effect size.